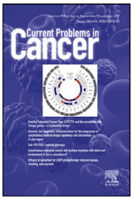
Current Problems in Cancer 43 (2019) 100464

Contents lists available at ScienceDirect

Current Problems in Cancer

journal homepage: www.elsevier.com/locate/cpcancer



Cognitive and emotional representations of pain in cancer patients at an inpatient unit and home palliative care

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ARTICLE INFO

Keywords:
Beliefs
Cancer
Pain
Palliative care
Treatment

ABSTRACT

Purpose: To compare symptomatic treatment at inpatient palliative care unit and at home in terms of: pain intensity; negative impact of pain on functioning in different areas of life; and beliefs about pain (cognitive and emotional aspects according to Leventhal's theory).
Patients: The sample consisted of 74 cancer patients qualified for palliative care at an inpatient unit (N = 53) and at home (N = 21).
Methods: Brief Pain Inventory––Short Form (measurement of pain intensity and pain interference with daily activities), Karnofsky Scale (performance status), Illness Perception Questionnaire for cognitive and emotional representations and beliefs about pain, and Hospital Anxiety and Depression Scale.
Results: Patients treated at inpatient unit and patients treated at home did not differ in terms of pain intensity, depression, and anxiety. The only significant differences between groups were the beliefs about pain. Patients with cancer in

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☆ **Author disclosure statement:** No competing financial interests exist.

☆☆ **Funding source**: Research and scientific work: ST 50 (02-0050/07/312).

★ **Conflicts of interest**: None.

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https://doi.org/10.1016/j.currproblcancer.2019.01.005
0147-0272/

home care were more convinced of pain treatment effectiveness but expressed higher level of distress related to pain. Patients convinced that pain can be treated more effectively were younger, the pain they experienced was less severe, and they were treated at home.

Conclusions: Effectiveness of symptomatic treatment is comparable in patients with cancer at inpatient unit and at home. Treatment at home is associated with stronger patient convictions that pain can be effectively treated and higher level of distress. In future studies, the source of higher distress intensity in patients treated at home may be further explored.

Introduction

The management of cancer patients in palliative (hospice) care at an inpatient palliative care unit (stationary hospice) and at home, aims at improving the quality of life (QoL) through effective prevention, meticulous evaluation, and possibly most effective treatment of pain and other bothersome symptoms and at providing broadly defined psychosocial and spiritual support for patients and caregivers (WHO, 2002). The decision as to which place of treatment should be chosen is very important for patients and their caregivers and is usually made with a lot of cautiousness. Research suggest that there is a preference for in-home treatment,[1] but the choice is individual and dependent on many factors, which comprise individualized and meticulous clinical evaluation, patients' preferences, and caregiving capabilities of the family. In a study comparing QoL of cancer patients treated at home, at an inpatient palliative care unit and a day care center, factors such as patients' age, Karnofsky performance status, physical, and emotional functioning allowed to classify patients correctly to aforementioned types of care in 67%, 59%, and 70%, respectively. All these factors should be taken into account when choosing a place of care.[2]

One of the main factors influencing patient's choice of place of care is usually a belief about the possibilities of receiving effective treatment of pain and other cancer symptoms. Effective pain and symptom management, inability to provide proper care at home by the family, and hope for improvement of subjectively perceived QoL and health status often underlie the patient's and/or caregivers' decision to transfer the patient to palliative care inpatient unit at hospital or to free standing stationary hospice.[3]

The aim of this study was to compare symptomatic treatment at an inpatient palliative care unit and at home in terms of: pain intensity; negative impact of pain on functioning in different areas of life; and beliefs about pain in relation to Leventhal's self-regulation theory.[4]

Patients and methods

Patients

The study sample comprised 74 advanced cancer patients treated at an inpatient palliative care unit ("stationary hospice"; N = 53) and at home (N = 21; "home hospice") from 1 academic center in Poznan, Poland. Patients under stationary and home care were in advanced stage of cancer and required constant medical care. All patients were administered below listed instruments once during palliative care provision at an inpatient unit and at home by a nurse. The study protocol was accepted by the Bioethics Committee of Poznan University of Medical Sciences and all patients provided written, informed consent before participation in the study.

Methods

The following instruments were used.

The Illness Perception Questionnaire

The Illness Perception Questionnaire was designed to asses beliefs about chronic pain and allows for assessment of cognitive representations of pain in 7 dimensions: Timeline (acute/chronic), consequences, personal control, treatment control, illness coherence, timeline cyclical, and negative emotional representations.[4-6]

The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) was used to assess the intensity of depressive symptoms. HADS meets the psychometric requirements and is adjusted for cancer patients.[7] It is frequently employed as a screening test allowing for early intervention in patients at risk of mental disorder. It was adapted to Polish conditions.[8]

Brief Pain Inventory-Short Form

Brief Pain Inventory-Short Form (BPI-SF) allows to measure pain intensity and pain interference–to what extent pain affects patients' life activities (general activity, mood, walking ability, normal work, relations with other people, sleep, and enjoyment of life).[9] By filling the questionnaire, patients assess not only pain intensity and pain interference with daily activities, but also the location of pain. Adequately reliable and accurate, BPI has been adapted to Polish conditions.[10]

Karnofsky performance status

Karnofsky is a scale for determining general performance status of cancer patients, ranging from 0 to 100, where 0 means death and 100 means normal condition. It was designed by David A. Karnofsky and Joseph H. Burchenal.[11]

Statistical analysis

Statistical analysis was performed with STATISTICA v.12 (StatSoft Inc, Gdansk, Poland). The statistical significance of between-group differences in means was estimated by t Student test for continuous variables or $\chi 2$ for categorical variables. Linear regression was performed to evaluate the effect of studied variables on illness perceptions.

Theory

Leventhal's theory provides grounds for understanding factors affecting how patients perceive risks related to a disease and its symptoms, and how this perception modifies their behavior related to coping with the disease. The essence of the self-regulation model, also known as common sense model of illness cognition, is the assumption that patients understand their illness and cope with it by creating mental representations containing combined cognitive and emotional components. Cognitive processes base on interpreting illness as a threat, and emotional processes compose a subjective reaction to this interpretation. Both processes remain in constant interaction. Cognitive components of an illness representation fall into 5 dimensions. *Identity* is the name a patient gives to the illness. *Cause* represents factors individually seen as responsible for developing illness. *Consequences* reflect the influence of illness on patient's life and activities. *Timeline* is an individual perception of the development of illness and of the time of its influence on patient's general condition. *Controllability* refers to beliefs about patient's ability to control treatment alone or with help from others.[4]

Table 1
Basic characteristics of patients—numbers and percentages are provided.

Variable	Place of treatment		P value
	Inpatient unit	Home	
Sex			
Women	28 (70.0%)	12 (30.0%)	0.737*
Men	25 (73.5%)	9 (26.5%)	
Altogether	53 (71.6%)	21 (28.4%)	
Age	59.98 (SD = 11.6)	66.28 (SD = 15.2)	0.058†
Education	18 (81.8%)	4 (18.2%)	0.217*
Primary	23 (62.2%)	14 (37.8%)	
High school	11 (78.6%)	3 (21.4%)	
Higher			
Place of residence			
Town/city	45 (69.2%)	20 (30.8%)	0.220*
Village	8 (88.9%)	1 (11.1%)	
Karnofsky	56.8 (os = 16.1)	48.1 (os = 11.6)	0.028†
Pain duration (mo)	19.4 (os = 23.7)	18.5 (os = 28.3)	0.895†

Statistics.

* P for χ^2.

† P for student's t-test.

Emotional representation reflects an assessment of a potential emotional impact of the disease. By analyzing information, a patient is able to develop a plan for managing emotions felt in reaction to the illness. The next stage is a copying strategy—reducing the illness or protecting against its negative aspects.[12]

Understanding beliefs and emotions in patients in advanced stage of the disease during symptomatic treatment, whose performance status is severely limited, assumes special significance for the treatment effectiveness and allows the interdisciplinary team of carers to better choose various places of care.[13]

Results

Table 1 presents a sociodemographic and clinical description of both patient groups.

Regarding sex, education, and place of residence, patients did not differ significantly between groups (inpatient unit vs home). In the area of age, a tendency towards higher values in the home-care group was found. Performance status measured with Karnofsky was found to be significantly different, with patients in home care being slightly less active (a lower Karnofsky score). The average duration of pain was not significantly different between both patient groups.

The results (Table 2) show that patients from the 2 groups did not differ in terms of pain intensity or pain interference (BPI-Short Form). Patients from these 2 groups also did not differ in terms of depression intensity (HADS). The only difference between patient groups lies in disparate beliefs about particular aspects of pain. In comparison to patients staying at an inpatient unit, patients in home care expressed beliefs about better treatment control in relation to pain ($t = 2.242$, $P < 0.05$). Patients treated at home also experienced more intense distress related to pain ($t = 2.142$, $P < 0.05$).

In the regression model, age, pain intensity, and place of treatment proved to be predictors of patients' beliefs about possible treatment control in terms of pain (Table 3). The statistically significant model allows for explaining approximately 31% of variance for the analyzed variable ($R^2 = 0.309$). Patients convinced that treatment of pain is more controllable were younger, they experienced less intense pain and they were treated at home. Anxiety and depression intensity were of no significance.

Table 2
Beliefs about pain (PCU-palliative care unit, HC-home care).

Variable	M PCU	SD PCU	M HC	SD HC	*t*	*P*
IPQ timeline	20.05	3.64	18.00	5.15	−1.669	
IPQ timeline cyclical	15.96	2.18	16.86	1.98	1.700	
IPQ consequences	24.96	3.32	25.29	3.82	0.3400	
IPQ personal control	17.40	2.61	16.89	2.13	−0.883	
IPQ treatment control	16.87	2.15	18.04	1.96	2.242	*
IPQ illness coherence	15.66	3.38	16.71	2.47	1.481	
IPQ emotional representations	23.74	3.72	25.29	2.33	2.142	*
HADS anxiety	10.17	4.48	10.67	4.44	0.512	
HADS depression	9.06	3.71	9.86	3.35	0.898	
BPI pain interference	4.72	2.09	5.83	2.13	2.023	
BPI pain intensity	3.11	1.87	3.20	2.24	0.247	
BPI pain at its worst	5.75	2.60	6.86	2.29	1.796	
BPI pain at its least	1.15	1.68	1.00	1.34	−0.405	
BPI pain on average	3.37	2.16	3.24	1.51	−0.285	
BPI pain right now	2.19	2.60	1.71	2.12	−0.810	

* $P < 0.05$, student's *t*-test.

Table 3
Regression model of treatment control in relation to pain.

Coefficient	Estimate β	*P*
Age	−0.038	0.027*
Sex (male)	−0.522	0.238
Place of care	−1.527	0.003†
Pain duration	0.004	0.609
Pain Intensity	−0.382	0.0102*
Pain Interference	0.051	0.663
HADS Anxiety	−0.091	0.2875
HADS Depression	−0.145	0.148

* $P < 0.05$.
† $P < 0.01$.

Discussion

In the field of palliative care of cancer patients, a growing demand and progressive improvement create a necessity for better understanding of patients' needs and key factors important to enhance quality of care.[14,15] One of patients' major needs is receiving an effective treatment of pain and other symptoms. Pain is the symptom most commonly associated with cancer and significantly affecting patients' and caregivers QoL.[16]

In this study, no differences were observed in pain intensity between patients at inpatient palliative care unit and home care, which may signify that in both groups, patients received proper care and effective symptom treatment including pain management. Although statistically insignificant, higher scores were observed among patients treated at home regarding pain interference with life activities and pain at its worst. Lower probability of experiencing severe pain in hospitals has been indicated in other studies, along with emphasizing no difference in the proportion of patients free from pain between the 2 types of care. Authors of the study suggest that conclusions on better coping with pain in hospital conditions should be drawn circumspectly and always with patient's age taken into account.[17]

Our previous research, similarly to the results obtained in this study, also showed no differences in terms of QoL (in physical and emotional aspects), tiredness, or experiencing pain among patients treated in different palliative care settings (inpatient unit, home, and day care center).[2] Other authors similarly emphasize similarities in the effectiveness of the 2 types of palliative care (in-patient and home) in different parameters, including QoL and pain.[18-20]

With the verified in numerous studies substantial similarity of pain treatment effectiveness between the 2 kinds of care, the differences in patients' individual beliefs assume greater importance. Patients receiving treatment at home are convinced about higher treatment control in relation to pain, but they also experience significantly greater emotional distress related to beliefs about pain.

Patients' locus of control in therapeutic processes often defines their sense of safety and level of stress. Feeling of control can positively modify psychological process of coping with pain. Antonovsky developed the concept of coherence referring to perceived comprehensiveness and sensibility of experience as well as to resourcefulness and ability to cope, which all play important role in the process of maintaining health.[21] More recently, a study on a group of cancer patients under stationary and home care indicated that significantly higher feeling of control over the effects of illness, medical care, and received treatment was characteristic of patients staying at home. The authors attribute it to a greater independence and freedom in this group, compared to patients in stationary care. The same study showed that a greater control over all aspects of the disease (along with better health condition and lower level of depressive symptoms) works as a predictor of a better QoL.[22]

Higher level of emotional distress related to pain, experienced by patients staying at home can bring an adverse effect. It was demonstrated in several studies that a stable and moderately strong connection between negative affect and reporting of somatic symptoms. The results are typically described as a connection between a characteristic of high negative affect and an elevated level of vigilance, with focusing on somatic sensations and lower pain threshold. Patients with low negative effect tend to ignore somatic sensations. According to Leventhal model, patients with high negative effect manifest a wider range of somatic symptoms of an illness representation due to their more intense emotional distress related to chronic disease. Also according to this model, in patients with chronic disease and with a higher level of negative affect, distress related to life events may activate illness representations and may dispose toward more frequent reporting of somatic symptoms.[23]

Many authors who base their research on the theory and model of self-regulation emphasize positive aspects of patients' active participation in the process of treatment where the patient is able to create an accurate representation of illness in relation to its name, duration, consequences, and their ability to control treatment. Research results confirm advantages of employing the theory also in treating patients with the most complex limitations.[24,25] Patients who strongly experience the diagnosis of their disease, its chronic presence, and incurability are able to understand its impact on their everyday life. For that reason, specific diagnosis of beliefs about pain seems as important as measuring the intensity of pain, especially in older patients. The results of our study also suggest that older patients with more severe pain intensity deserve special attention as these 2 variables correlate with perceived lower level of treatment control related to pain.

Conclusion

To our knowledge, this is a first study which demonstrated that home care is correlated with the positive effect of advanced cancer patients experiencing a higher level of pain treatment control but also a negative effect of a higher level of distress related to pain. The possible sources might be anxiety related to the absence of a doctor or nurse, a possibility of being transferred to an inpatient unit palliative unit or hospital, and worries about inability to act in the case of breakthrough or episodic pain attacks. Although statistically insignificant, a more intense pain at its worst and more pain interference with life activities among cancer patients treated at home might potentially explain higher level of distress in this patient group. Future studies may further explore in more detail sources of distress related to pain.

Limitations of the study include small study sample, especially those treated at an inpatient unit and recruiting patients from a single academic center. Further limitations comprise a single assessment during the care without baseline evaluation. However, it may also be seen as an advantage as it is quite similar to a real life conditions encountered in cancer patients during stationary and home palliative care. Another limitation may be selection of those patients who agree to fill in all questionnaires used in this study, which may be a source of bias.

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